










# Patient-Reported Experiences after Acute Kidney Injury across Multiple Health-Related Quality-of-Life Domains

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## Key Points

- Eighty-four percent of respondents reported that the AKI episode was very/extremely impactful on physical/emotional health.
- Fifty-seven percent reported being very/extremely concerned about AKI effects on work, and 67% were concerned about AKI effects on family.
- Future research should incorporate more comprehensive HRQoL measures and providers should give more information to patients about AKI.

## Abstract

**Background** Investigations of health-related quality of life (HRQoL) in AKI have been limited in number, size, and domains assessed. We surveyed AKI survivors to describe the range of HRQoL AKI-related experiences and examined potential differences in AKI effects by sex and age at AKI episode.

**Methods** AKI survivors among American Association of Kidney Patients completed an anonymous online survey in September 2020. We assessed: (1) sociodemographic characteristics; (2) effects of AKI—physical, emotional, social; and (3) perceptions about interactions with health care providers using quantitative and qualitative items.

**Results** Respondents were 124 adult AKI survivors. Eighty-four percent reported that the AKI episode was very/extremely impactful on physical/emotional health. Fifty-seven percent reported being very/extremely concerned about AKI effects on work, and 67% were concerned about AKI effects on family. Only 52% of respondents rated medical team communication as very/extremely good. Individuals aged 22–65 years at AKI episode were more likely than younger/older counterparts to rate the AKI episode as highly impactful overall (90% versus 63% younger and 75% older individuals;  $P=0.04$ ), more impactful on family (78% versus 50% and 46%;  $P=0.008$ ), and more impactful on work (74% versus 38% and 10%;  $P<0.001$ ). Limitations of this work include convenience sampling, retrospective data collection, and unknown AKI severity.

**Conclusions** These findings are a critical step forward in understanding the range of AKI experiences/consequences. Future research should incorporate more comprehensive HRQoL measures, and health care professionals should consider providing more information in their patient communication about AKI and follow-up.

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## Introduction

AKI is a significant public health problem in the United States, with incidence rates estimated at 18 per 1000 individuals (1). AKI affects approximately 60% of all intensive care unit (ICU) patients (2) and complicates non-ICU hospitalizations, producing significantly worse short- and long-term outcomes. Approximately 20% of patients with AKI are readmitted within 30 days after their index hospitalization with an elevated risk of acute myocardial infarction and congestive heart failure (3). The development of new-onset CKD or worsening of preexisting CKD occurs in approximately 30% of patients surviving an episode of AKI and is associated with increased risk of progression to kidney failure (1,3–7).

There is also evidence that individuals who survive AKI have poorer quality of life and consume a greater proportion of health care resources than their healthy counterparts (8). Our own findings as part of the Veterans Affairs/National Institutes of Health Acute Renal Failure Network study indicate that 27% of AKI survivors had a severely compromised health utility index at 60 days, similar to what is considered by the general population to be equivalent to or worse than death (9). An additional handful of studies that have examined short- and longer-term health-related quality of life (HRQoL) among AKI survivors have generally found that (1) there are both physical and mental health effects of AKI, and (2) poorer AKI-related HRQoL is linked to greater mortality (9–17). In a systematic review, Villeneuve *et al.* (18) reported that HRQoL among AKI survivors who received renal replacement therapy in the ICU was lower than that of population norms but did not differ from that of other ICU patients. The studies included in this systematic review and other investigations of HRQoL in AKI have assessed HRQoL and function using either generic HRQoL measures (*e.g.*, SF-36 [19], EuroQoL [18], or Health Utilities Index [20]) or measures designed to assess HRQoL in the context of CKD. Although these measures provide valuable information about the general patient-reported health effects of AKI, they do not provide especially nuanced information about the physical, emotional, and social consequences of AKI. Specifically, this prior work has not identified the most impactful HRQoL elements of the factors of the AKI experience, separated AKI's effect on employment versus return to usual activities, explored health care communication quality in the context of AKI, or evaluated concern about medical costs. Furthermore, a systematic review of studies focused on a broad range of kidney diseases found that patient-reported HRQoL is often not the focus of these investigations and concluded that it is imperative to elevate it as a research priority to improve patient-centered care (20).

Our goals for this investigation were to survey AKI survivors in order to (1) describe the range of AKI-related HRQoL experiences—physical/functional, emotional, and social (*e.g.*, family and work), physical/functional, emotional, social, and health care communication, and (2) examine potential differences in effects of AKI by sex and age at AKI episode. We expected that findings from this diverse sample would provide information about important aspects of the AKI experience that may have been under-investigated in previous research and form a foundation for further refinement of instruments designed to assess HRQoL in the context of AKI.

## Materials and Methods

### Human Subjects Research Protection

This investigation was reviewed by the Institutional Review Board at the University of Pittsburgh and was determined to be exempt from Institutional Review Board oversight.

### Participants and Study Design

This cross-sectional investigation included AKI survivors who were members of the American Association of Kidney Patients (AAKP) and who responded to an online Qualtrics-based survey between October 14, 2020, and October 26, 2020. An anonymous survey link was distributed to all members by AAKP leadership via email and was followed by three email reminders. Although the AAKP includes individuals with a range of kidney diseases, the survey included a screening question to ensure that only AKI survivors responded to the full survey.

### Study Measures

Given the lack of existing validated measures to evaluate HRQoL specifically in AKI, our authors developed a novel survey in collaboration with content and psychometric/measurement experts who were all co-investigators. A key strength of the investigation is the involvement of AKI patient survivors (co-authors R.K. and P.C.) in the development and refinement of the item sets that were used in the investigation and content validity review and revision by our full study team, which included specialists in all aspects of AKI disease and treatment, HRQoL, patient-reported measurement, survey design/deployment, and biostatistics. The English language survey was designed to minimize patient burden and had an expected time for completion of <10 minutes. The survey included three categories of participant characteristics: (1) sociodemographic characteristics, (2) effects of AKI—physical, emotional, social (*e.g.*, work and family), and (3) perceptions about interactions with health care providers (see Supplemental Material for study questionnaire).

Sociodemographic characteristics included age at first AKI episode, current age, education level, sex, and race/ethnicity. For examination of associations between age at first AKI episode and other variables, age was trichotomized as 0–21, 22–65, and >65 years. HRQoL effects of AKI were overall physical and emotional effects of AKI (four-point scale; “slightly impactful” to “extremely impactful”), AKI experience checklist (check all that apply; 16 physical/functional, emotional, and care-related plus “other”), top three effects/difficulties of AKI selected from the list of 16 potential effects, concern about family (five-point scale; “not at all” to “extremely”) plus an open-ended follow-up, concern about work (five-point scale; “not at all” to “extremely”) plus an open-ended follow-up, and quality of health care information communication (five-point scale; “not at all good” to “extremely good”).

### Statistical Analyses

Data were cleaned and exported from Qualtrics to IBM SPSS Statistics for Windows v22.0 (IBM Corp., Armonk, NY) for analysis. Percentages were used to describe categorical variables, and means and SD were used to describe

continuous variables. Responses to open-ended questions were initially reviewed and grouped into themes by one of the authors (V.K.) and then reviewed separately for appropriate categorization of response by two additional co-authors (G.E.S. and J.G.B.). The few differences in coding (<5% of total) were resolved by discussion among these three authors. For bivariate comparisons—sex and age at AKI episode by key effect variables—we dichotomized the Likert scales (“very” and “extremely” versus the other three response categories). For these same analyses, age at AKI episode was trichotomized: 0–21 years, 22–65 years, and  $\geq 65$  years of age. Differences by sex and age at first AKI episode were examined using chi-squared analyses.

## Results

### Participants

In October 2020, members of the AAKP who opted to participate in quick-turnaround survey opportunities ( $N=23,582$ ) received an email invitation to participate in a short anonymous survey about experiences with AKI and three follow-up reminders. A total of 124 AKI survivors completed the survey during a 2-week window. Table 1 shows the sociodemographic characteristics of the study participants. The mean age at first AKI episode was 53 years, with a median of 58 years, but there was wide variation ( $SD=19$  years; range=2–82 years). Table 1 also reports the

categorical version of the variable, with the majority of respondents (78%) in the middle age category (22–65 years) at the time of their first AKI episode. Mean current age was 62 years, with a median of 63 years ( $SD=13$  years; range=23–84 years). Fifty-six percent of the sample were women, and 77% were White. Fifty-five percent of respondents had completed a bachelor’s degree or more.

### Overall Effects/Experiences of AKI

Table 2 presents responses to questions about the effect of AKI. Eighty-four percent (95% confidence interval [CI], 76% to 90%) of respondents reported that the AKI episode was either “very” or “extremely” impactful on their physical and emotional health. In terms of specific effects, >50% of respondents reported not feeling well physically or feeling weak or tired. An additional >30% reported (1) feeling unable to do daily activities, (2) feeling anxious or stressed, (3) feeling unable to do fun/recreational activities, (4) having trouble sleeping, (5) not feeling well emotionally, or (6) feeling down or depressed. Smaller percentages (15%–25%) reported (1) problems with coordination of care and with receiving information about AKI, (2) problems with dietary restrictions, and (3) concern about medical costs. When respondents were asked to select the top three AKI effects from the list of 16 potential effects, the most frequently endorsed responses were not feeling well physically (48%), feeling weak or tired (36%), and feeling unable to do daily activities (28%).

**Table 1. Participant sociodemographic characteristics**

Participant Characteristic	Total N=124	Missing, N	% or Mean (SD)
Age, yr, at first AKI episode (categorical)			
0–21	8	9	7
22–65	78		68
>65	29		25
Current age, yr, mean (SD)	155	26	61.69 (13.10)
Difference, yr, between age at first AKI and current age			
0–5	50	30	53
6–10	15		16
11–15	5		5
>15	24		26
Sex			
Men	42	26	43
Women	55		56
Prefer to self-describe	1		1
Race and ethnic background			
Hispanic or Latino	3	27	3
Black	9		9
Asian or Pacific Islander	3		3
White	75		77
Native American	1		1
Mixed or multiple race or ethnicity	4		4
Other	2		2
Formal education completed			
Some high school (HS)	1	27	1
HS graduate or GED	10		10
Trade school or business school post HS	7		7
Some college	26		27
Bachelor’s degree	18		19
Some graduate/professional school post bachelor’s	9		9
Graduate or professional degree	26		27

**Table 2. Participant-reported effect of AKI**

AKI Effect	Total N=124	Missing, <i>n</i>	% or Mean (SD)
Effect of AKI episode on physical and emotional health			
Extremely impactful	68	0	55
Very impactful	36		29
Moderately impactful	12		10
Slightly impactful	8		7
Factors endorsed as part of AKI experience (check all that apply)			
Not feeling well physically	82	N/A <sup>a</sup>	53
Feeling weak or tired	79		51
Feeling unable to do daily activities	58		37
Feeling anxious or stressed	56		36
Feeling unable to do fun/recreational activities	55		36
Having trouble sleeping	52		34
Not feeling well emotionally	49		32
Feeling down or depressed	49		32
Having symptoms related to AKI	45		29
Feeling like you didn't have enough information about AKI	34		22
Having trouble with restrictions on what you could eat	33		21
Feeling like the doctors didn't coordinate care—weren't talking to each other	31		20
Having trouble getting information from health care providers	26		17
Having concerns about who was going to cover health care costs	24		16
Having trouble getting information about AKI	22		14
Other (please specify)	19		12
Feeling unsupported by friends/family	15		10
During/after AKI episode, how concerned were you about the effects of the illness on your <i>family</i> life?			
Extremely concerned	42	19	40
Very concerned	28		27
Moderately concerned	19		18
Slightly concerned	8		8
Not at all concerned	8		8
During/after AKI episode, how concerned were you about the effects of the illness on your <i>work</i> life?			
Extremely concerned	40	24	40
Very concerned	17		17
Moderately concerned	5		5
Slightly concerned	5		5
Not at all concerned	33		33
How well did the medical team communicate about AKI, including information about treatment and longer-term laboratory tests and follow-up?			
Extremely well	31	24	31
Very well	21		21
Moderately well	18		18
Slightly well	15		15
Not at all well	15		15

<sup>a</sup>Missing values are not presented for this question because it was “check all that apply.”

### Physical/Functional Experiences of AKI

Physical effects of AKI were the most frequently endorsed from the 16-item checklist. Four of the top five most frequently endorsed effects (Table 2) referenced physical/functional limitations, including not feeling well physically, feeling weak/tired, feeling unable to do daily activities, and feeling unable to do fun/recreational activities. In addition, one of the main categories of responses when respondents were asked an open-ended question about “other” effects that were not listed was AKI symptoms, including nausea, trouble walking, and limited appetite. Examples of quotes representing these themes and themes from other experience categories are shown in Table 3.

### Emotional Experiences of AKI

Emotional effects of AKI were also frequently endorsed by respondents. The three most commonly endorsed emotional effects from the 16-item checklist were feeling anxious or stressed (36%), not feeling well emotionally (32%), and feeling down or depressed (32%). In addition, in their responses to open-ended questions, participants also reported depression about potential inability to return to and maintain an active lifestyle and fears about future loss of function in one or both of their kidneys (Table 3).

### Family-Related AKI Experiences

Sixty-seven percent (95% CI, 57% to 76%) of respondents reported being very/extremely concerned about AKI



illness effects on their families. This question generated the highest number of open-ended descriptive responses about the specific types of family effects. Several themes emerged from these open-ended responses, including (1) feeling rejected/misunderstood by family, (2) feeling like a burden on family, (3) not being able to support family, and (4) loss of independence (Table 3).

### Work-Related AKI Experiences

Fifty-seven percent (95% CI, 47% to 67%) of respondents reported being very/extremely concerned about AKI illness effects on their work. Several themes emerged in the open-ended responses to the question about work-related effects, including (1) difficulty scheduling treatment, (2) concern about declining performance, (3) concern about losing job, and (4) concern about long-term disability (Table 3).

### Health Care–Related AKI Experiences

Only 52% (95% CI, 42% to 62%) of respondents reported that the medical team communicated AKI information—including information about treatment and longer-term laboratory tests and follow-up—very/extremely well. Key themes that emerged from the open-ended follow-up question were (1) overall lack of information and uncertainty about AKI, and (2) mismanagement and poor communication by health care professionals (Table 3).

### Differences by Sex and Age at AKI Episode

We examined potential sex differences and differences by age at AKI episode across four key quantitative questions: overall effect of AKI, effect on family, effect on work, and quality of health care communication (Table 4). Although no sex differences were significant at  $P \leq 0.05$ , women tended to be more likely than men to rate the AKI episode as highly impactful (93% versus 76%;  $P = 0.06$ ) and less likely to indicate that the medical team communicated AKI medical information well (42% versus 64%;  $P = 0.06$ ). Individuals between 22 and 65 years of age when the AKI episode occurred (middle age category) were more likely than their younger and older counterparts to rate the AKI episode as highly impactful overall (90% versus 63% youngest age group and 75% oldest age group;  $P = 0.04$ ), more impactful on family (78% versus 50% and 46%;  $P = 0.008$ ), and more impactful on work (74% versus 38% and 10%;  $P < 0.001$ ). Time since AKI episode (*i.e.*, difference between age at first AKI episode and current age) was not associated with overall reported effect of AKI episode.

## Discussion

The central goals of this investigation were to describe a broad range of physical, emotional, and social effects of AKI and to examine potential differences in these areas by sex and age at AKI onset. The few other investigations of HRQoL after AKI have generally been small, single center, and limited primarily to assessment of physical and mental health effects of AKI using generic HRQoL instruments (8). A particular strength of this investigation was the involvement of AKI survivors in all project phases, from the

refinement of the survey instrument through interpretation of the findings, which allowed us to include areas of HRQoL that may be particularly affected by AKI and important to patients—*e.g.*, effects on work and family—but under-investigated in previous research.

The vast majority of participants (84%) reported that the AKI episode was very/extremely impactful on their physical/emotional health. Not surprisingly, the most frequently cited effects were physical; the top three effects were not feeling well physically, feeling weak/tired, and not being able to engage in daily activities. However, these physical effects were followed closely in frequency of reporting by emotional effects, including feeling anxious/stressed, having trouble sleeping, and not feeling well emotionally. It should be noted that other investigators have found that despite the effect of AKI, longer-term HRQoL is often rated as satisfactory or acceptable in this group (13,21,22,23).

These physical and emotional effects have been relatively well established, and a particularly novel aspect of our findings is the patient-reported effect of AKI on work and family. Responses to the closed-ended questions about the effect on work and family indicated that nearly 60% of survivors were very/extremely concerned about the effect of AKI on work and nearly 70% were concerned about the effect on family. The work-concern findings are consistent with findings from Morsch *et al.* (17) that only 28% of AKI survivors returned to work at 9 months after the episode. They are somewhat less consistent with findings from Morgera *et al.* (23) that indicated 69% of patients employed before the AKI episode were able to return to work; however, our question was about work-related concern, not actual return to work, and could have included concern about work-related limitations even if work was resumed. A small subset of respondents (approximately 16%) reported concerns about health care cost coverage of their AKI hospitalization. This is lower than the rate reported by Khandelwal *et al.* (24) (approximately 43%) and may be due to the fact that that investigation involved ICU patients, whereas ours likely involved a mix of AKI severity types.

Participants were also most likely to enter open-ended explanations and descriptions about AKI experiences in response to these questions, and many of the responses clearly evoked deep emotions. In particular, feeling misunderstood/neglected by family, feeling like a burden, and not being able to attend family functions and perform adequately at work were issues described by multiple participants. Finally, only 52% of survivors rated communication with the medical team around AKI as very/extremely good. Open-ended responses cited poor medical management that may have led to the AKI episode and lack of communication/information about AKI itself and how to manage/treat it. Given the high risk of rehospitalizations, cardiovascular complications, and risk for CKD among AKI patients, this perceived gap in communication/education should be addressed. The importance of these three facets of the AKI experience in our research—effects on work, effects on family, and poor communication with health care professionals—is a novel finding and implies that these factors should likely be incorporated into patient-centered research in this area. Further, the themes that emerged from these open-ended questions and the

**Table 3. Qualitative themes and representative participant quotations**

Physical/functional experiences	<ul style="list-style-type: none"> <li>• “Nausea, couldn’t eat”</li> <li>• “Urinating very frequently but with small volume”</li> <li>• “Lost taste and was unable to walk even very short distances”</li> </ul>
Emotional experiences	<ul style="list-style-type: none"> <li>• “Depressed about future ability to maintain active lifestyle”</li> <li>• “Ability to return to same level activity before operation”</li> <li>• “I lost one of my kidneys and worry what if I lost the other one”</li> </ul>
Family-related experiences	<p><b>Feeling rejected/misunderstood by family</b></p> <ul style="list-style-type: none"> <li>• “My family have never been understanding about my kidney disease and they didn’t understand why I was so tired and feeling ill”</li> <li>• “My grown kids were very unkind to me; they never came to see me or even phoned”</li> </ul> <p><b>Feeling like a burden on family</b></p> <ul style="list-style-type: none"> <li>• “Them taking on extra responsibilities connected to my health”</li> <li>• “The way they had to go out of their way to help me”</li> </ul> <p><b>Not being able to spend time with family</b></p> <ul style="list-style-type: none"> <li>• “Not being able to spend time with a dying family member”</li> <li>• “Not being able to enjoy life with those I love”</li> </ul> <p><b>Loss of independence</b></p> <ul style="list-style-type: none"> <li>• “Concerned that I might not be able to continue to be independent”</li> <li>• “Getting out and doing errands by myself”</li> </ul>
Work-related experiences	<p><b>Scheduling conflicts</b></p> <ul style="list-style-type: none"> <li>• “Not being able to work and knowing how my work would accommodate my dialysis schedule”</li> <li>• “Scheduling treatment”</li> </ul> <p><b>Concern about declining performance</b></p> <ul style="list-style-type: none"> <li>• “My lack of performing my job at the level of pre-AKI”</li> <li>• “My symptoms affected my work performance”</li> </ul> <p><b>Concern about losing job</b></p> <ul style="list-style-type: none"> <li>• “If I were to die or be unable to work, my husband and daughter would lose both my income and health insurance”</li> <li>• “Being fired and having loss of medical coverage”</li> <li>• “Being forced into retirement”</li> </ul> <p><b>Concern about long-term disability</b></p> <ul style="list-style-type: none"> <li>• “Potential for having a permanent disability”</li> <li>• “Progress to kidney failure and need to RRT”</li> </ul>
Health care–related experiences	<p><b>Lack of information and uncertainty</b></p> <ul style="list-style-type: none"> <li>• “Didn’t get all necessary information”</li> <li>• “Nobody really knew the answer”</li> <li>• “I did not know enough to even ask basic questions. I did not know what kind of kidney disease I had.”</li> <li>• “Frustrating inaccuracies about renal diets”</li> </ul> <p><b>Mismanagement and lack of communication</b></p> <ul style="list-style-type: none"> <li>• “My doctors at the time didn’t explain the seriousness of the AKI”</li> <li>• “Very poor diagnosis and care at initial stages of onset”</li> <li>• “I learned by reading an unrelated appointment summary that my kidneys had suffered an acute injury caused by an adverse reaction to anesthesia during a complex back surgery.”</li> <li>• “Lack of understanding early on in diagnosing the medical condition and managing the kidney damage caused by it resulted in loss of kidney function and might have been avoided. Now on dialysis.”</li> <li>• “The damage was caused by the surgeons when they did a spinal fusion surgery”</li> </ul>

**Table 4. Overall effect: Family and work concerns by sex and age at first AKI episode**

AKI Effect, %	Sex			Age at First AKI, yr			
	Women	Men	Chi-Squared Test	<21	21–65	>65	Chi-Squared Test
Effect of AKI: extremely/very impactful	93	76	5.49	63	90	75	6.42 <sup>a</sup>
Concern about family: extremely/very concerned	69	60	1.50	50	78	46	9.76 <sup>b</sup>
Concern about work: extremely/very concerned	59	52	1.23	38	74	10	27.97 <sup>c</sup>
Medical team communication: extremely/very well	42	64	5.75	75	52	47	1.85

<sup>a</sup> $P \leq 0.05$ .  
<sup>b</sup> $P \leq 0.01$ .  
<sup>c</sup> $P \leq 0.001$ .

specific items within these domains reflect important aspects that should be considered for inclusion in the development of AKI-specific HRQoL questionnaires.

Women and adults aged 22–65 years at AKI episode (as opposed to younger and older age groups) tended to report that the AKI experience was more physically/emotionally impactful overall; this middle age group also reported more of an effect on work and family. This latter finding is not surprising, given that this age group is more likely to be actively working and caring for family at home, but it does imply that interventions to improve HRQoL should recognize and focus on the extra effects of AKI among this group. Women tended to report having worse experiences in communicating with the medical team—a finding that should be explored in more detail in future research.

There are a few limitations to this research. First, this was a convenience sample derived from the membership of the AAKP. It is highly likely that AAKP members are more knowledgeable about AKI in general than their non-member counterparts and may also be more likely to have residual kidney impairment. They also likely have more formal education—27% of the sample had graduate or professional degrees. This may have allowed our respondents to understand better and report some of the medical aspects of their experiences and perhaps that they had more severe or chronic AKI experiences. It could suggest, however, that a nonmember population would be even less informed and more frustrated by their AKI experiences. We also have no objective measure of AKI severity among this group—future work in this area could estimate severity by asking, for example, whether respondents required dialysis during their AKI episode and whether they currently have complete/incomplete/no return of kidney function to their best knowledge. Second, although we had good sex representation, the sample was not particularly racially/ethnically diverse—77% of the sample was non-Hispanic white. This limitation is important to address in future research that would include broader race/ethnic diversity among AKI survivors. Third, the data are retrospective in nature, which may have affected respondents' ability to recall the AKI episode accurately, suggesting that prospective studies of HRQoL in AKI are needed. Finally, although we asked specifically about symptoms related to AKI, many AKI patients have other comorbidities or acute illness at the time of AKI—and progression to chronic kidney disease for some patients—that may have independently contributed to symptom experiences.

Despite the potential limitations of the investigation, these findings are a critical step forward in our understanding of the range of AKI experiences/consequences. As such, they suggest that additional research using more nuanced and comprehensive HRQoL measures administered early in the AKI experience and followed longitudinally is essential. If these or new items/measures are developed to assess these understudied domains further, it will be important to evaluate their psychometric properties, including content validity and reliability. Additionally, health care professionals should be more proactive and informative in their patient communication about AKI and in their post-AKI follow-up, and more effective means of patient education and communication regarding AKI are needed to address patient concerns.

#### Disclosures

P. Conway reports the following: Current Employer: Conway Strategies Global; Honoraria: 2018–2021: University of California Irvine; Arizona Advice Collaborative/Arizona Department of Health; Kidney Research Institute & Center for Dialysis Innovation, University of Washington; Bayer; Novartis, Global Transplant Patient Reported Outcome Measure Patient Advisory Committee; Scientific Advisor or Membership: Chair Policy/Global Affairs, Past President, American Association of Kidney Patients; Chair, Patient Engagement Advisory Committee, Food and Drug Administration; Congressionally Directed Medical Research Program, Department of Defense; Patient Voice Editor, Clinical Journal of the American Society of Nephrology; Kidney Health Initiative; Nephrology Specialty Board, American Board of Internal Medicine; External Expert Panel, Kidney Precision Medicine Project, National Institutes of Health; and Other Interests/Relationships: Contract Management Board, Renal Data System; Co-Chair, AAKP/George Washington University School of Medicine & Health Sciences Global Summit on Kidney Disease Innovations; Participant Advisory Board, University of Pittsburgh/NIH Acute Kidney Injury Study; World Health Organization Lived Experience Advocacy Research; Centers for Disease Control, Health Infections Control Practices Advisory Committee; FDA Cardiovascular Devices Advisory Committee; FDA Medical Devices Advisory Committee. L.F. Fried reports consultancy agreements with Bayer and is on the data safety monitoring boards for CSL Behring and Novonordisk. M. Jhamb reports research funding from the Arbor Research Collaborative for Health, Bayer LLC, Dialysis Clinic, Inc., and NIH, and is a member of the ASN and the National Kidney Foundation. S.L. Kane-Gill reports research funding from the National Institute of

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## Data Sharing Statement

All data are included in the manuscript and/or supporting information.

## Author Contributions

K.Z. Abebe, J.G. Bruce, L.F. Fried, S.L. Kane-Gill, V. Kuniyil, J.N. Murphy, P.M. Palevsky, C.M. Puttarajappa, and G.E. Switzer conceptualized the study; K.Z. Abebe, J.A. Kellum, P.T. Conway, L.F. Fried, S.L. Kane-Gill, R. Knight, P.M. Palevsky, C.M. Puttarajappa, and G.E. Switzer carried out the investigation; K.Z. Abebe, J.G. Bruce, L.F. Fried, S.L. Kane-Gill, V. Kuniyil, P.M. Palevsky, C.M. Puttarajappa, and G.E. Switzer were responsible for the methodology; J.G. Bruce, V. Kuniyil, and G.E. Switzer curated the data; J.G. Bruce, V. Kuniyil, C.M. Puttarajappa, and G.E. Switzer were responsible for the formal analysis; J.G. Bruce and V. Kuniyil were responsible for project administration; P.T. Conway, R. Knight, and G.E. Switzer were responsible for resources and supervision. C.M. Puttarajappa and G.E. Switzer were responsible for validation; G.E. Switzer was responsible for software and wrote the original draft of the manuscript; and all authors were responsible for reviewing and editing the manuscript.

## Supplemental Material

This article contains supplemental material online at <http://kidney360.asnjournals.org/lookup/suppl/doi:10.34067/KID.0002782021/-/DCSupplemental>.

## Questionnaire

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